

August 23, 1999

The Honorable John Dingell U.S. House of Representatives 2328 Rayburn House Office Building Washington, DC 20515-2216

Dear Representative Dingell:

On behalf of the Paralysis Society of America (PSA), I am writing to voice support for H.R. 2723, the Bipartisan Consensus Managed Care Improvement Act of 1999.

We are pleased to see that the consensus bill combines the patient protections found in the major managed care reform bills introduced in the House this year, including H.R. 216, the Quality Care Act, and H.R. 358, the Patients' Bill of Rights. We also note the importance of H.R. 2723 as a bipartisan bill. Legislators who support this bipartisan bill recognize the importance of a health care system that balances the cost of service delivery without sacrificing individual patient needs.

PSA's membership of more than 19,800 people consists of individuals with spinal cord injury or disease, their family members and caregivers, health care professionals, and others with an interest in the disciplines of spinal cord medicine and paralysis. As you can imagine, the outcome of patient protection legislation speaks directly to the vested interest of our membership.

Particular attention is given to those portions of the legislation covering freedom of choice, specialists, and external appeals, clinical trials and privacy. Also of interest to our membership are the sections covering continued care, freedom of communication, clinical trials reform, incentives to deny care, and privacy.

- PSA members want the right to freely choose and/or change their doctor and hospital.
- PSA members want the right to see a specialist if they and their doctor determine the need is paramount to managing the complex health care needs of people with spinal cord dysfunction.

- PSA members want the right to a second and third opinion following denial of coverage by a health plan, at no cost to the patient.
- PSA members should not be forced to change doctors and hospitals while in the midst of a course of treatment for a health care problem.
- Doctors must be able to talk freely with patients without fearing repercussions from health plans. Every doctor should be free to discuss anything relative to a patient's health with the patient, even if the information may be negative towards the health plan. Health plans must not be permitted to use tactics that discriminate against doctors for cooperation in patient advocacy, such as threats of firing, disciplinary action and by providing incentives to deny care.
- PSA members should be able to participate in clinical trials that may maximize their independence and quality of life without undue interference from their health plan.
- PSA members are concerned about their right to privacy. No medical information on a patient should be released without the patient's approval.

The right to quality health care and patient protection is of primary importance to the members of the Paralysis Society of America. PSA offers its support, and will gladly assist you in any way we can to ensure that H.R. 2723 is enacted into law.

Sincerely,

Nancy Starnes

Director

c: Homer S. Townsend, President

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